EMERGENCY MANAGEMENT OF MYASTHENIA GRAVIS

MYASTHENIA GRAVIS FOUNDATION OF AMERICA

Information and guidance for people with MG, families and caregivers

www.Myasthenia.org

Emergency Management Of Myasthenia Gravis:

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Clinical Manifestations of Myasthenia Gravis (MG)

Myasthenia gravis (MG) is a rare neuromuscular disorder that causes weakness of voluntary muscles. Symptoms of MG can include eyelid drooping (ptosis), opposing eye movements and double vision, slurred speech, difficulty chewing and swallowing, neck, arm and leg weakness. When weakness is severe, there may be trouble walking and breathing. This muscle weakness may fluctuate over time and throughout the course of the day. Weakness can be mild or severe. Individuals with MG usually feel stronger in the morning or after a period of rest. Prolonged activity or repeated use of affected muscles can increase weakness. Treatments for MG include symptomatic therapy and/or immunosuppressant medications.

Triggers which may worsen MG muscle weakness include:

Medications

- High doses of steroids
- IV magnesium
- Some antibiotics
- Certain heart/blood pressure medications
- Some general anesthetics and paralytics
- Botulinum toxin
- Stopping or reducing medications used to treat MG

Illness or infection

Heat

Stress from trauma or surgery

MG Crisis vs. MG Flare

MYASTHENIC CRISIS affects a small percentage of people with MG. It occurs when the respiratory muscles get too weak to move enough air in and out of the lungs. The person with MG is unable to breathe and a machine (ventilator) is necessary to help them breathe. The machine may do this through a tube into the airway (endotracheal intubation) or a tight-fitting mask on the face (BiPAP). Myasthenic crisis involves the respiratory muscles so it is different from an MG flare (exacerbation).

MG FLARE or "exacerbation" occurs when there is worsening of some or all muscles throughout the body, but assistance is not required for breathing. MG flares vary from person to person but may include worsened double vision, slurred speech, increased arm weakness, falling, unsteady walking, and difficulty swallowing. *Many muscles throughout the body may weaken during an MG exacerbation but myasthenic crisis refers specifically to severe, potentially life-threatening weakness of respiratory muscles*. Myasthenic crisis typically develops after days to weeks of worsening symptoms. Rarely, MG crisis can develop more quickly. It is important to seek medical care immediately when symptoms of possible MG crisis are present.

How to tell if an MG crisis is developing:

Sometimes it is hard to tell if shortness of breath is due MG muscle weakness, another lung disease, heart problems or even anxiety. Signs that breathing function may be worsening due to MG include:

- Difficulty lying flat in bed without feeling short of breath
- Rapid shallow breathing (especially more than 25 breaths/minute)
- Having to pause in the middle of a sentence to take a breath
- Weak cough, especially when there is trouble clearing mucus/saliva from the throat
- Increase in slurred speech or difficulty chewing and swallowing
- Trouble holding up head due to neck weakness
- Significantly worsening arm or leg weakness in addition to shortness of breath
- Muscles between the ribs, around the neck and the abdomen pull in during breathing
- Cannot count out loud past 20 after a full breath of air (single breath count)

SEEK IMMEDIATE MEDICAL HELP WHEN FEELING SHORT OF BREATH, PARTICULARLY WITH THE ADDITIONAL SIGNS AND SYMPTOMS LISTED ABOVE.

Important note about pulse oximeters (pulse ox):

Pulse oximeters are one widely available tool used by healthcare professionals to assess respiratory status. People can also buy small monitors for home use. A pulse oximetry result < 90% (a "low pulse ox") indicates that someone's breathing is impaired. **However, a "low pulse ox" is a late finding in respiratory dysfunction related to MG and more reliably detects problems related to other lung and heart conditions. Direct measures of respiratory muscle strength should be used as the most reliable assessment of respiratory function for people with MG.** People with MG can have significant respiratory dysfunction and still have a normal "pulse ox."

Emergency Assistance

Some 911 call centers accept text messaging and can register someone's medical information in their database. You can check to see what options are available in your area. If someone is unable to speak when calling 911, the operator will identify the location and send help. First responders must easily be able to see the house address from the street, especially at night. A flashing or colorful front house light can help first responders identify where to go. Some medical alert programs can put a lock box on the door. In case of emergency, paramedics will have the access number so that they can enter the home.

An ambulance is typically called if the patient is too ill to speak, breathing assistance is needed, or transport from friends or family is not feasible.

If the patient has a BiPAP machine at home, bring it to the hospital. People with MG often find it helpful to have an updated sheet or packet of medical information ready in case of emergency. Information that you can include:

- Contact information for all physicians
- Information about any implanted devices (i.e. IV port, pacemaker)
- Emergency contact list
- MG information for providers
- ***Cautionary Drugs for MG*** handout found at myasthenia.org
- Medical history & hospital records

- Complete medication list – including supplements and OTC medications
- Health insurance cards
- Medical power of attorney forms (if applicable)
- Advance directive papers (if applicable)

In the Emergency Room/ Department

It can be very helpful for the medical team in the emergency department to call your regular MG neurologist for more information. If there is significant worsening of MG, the emergency team will also often consult the neurologist at the hospital. They will be thinking about next steps in treatment and what might have triggered a worsening of MG. A family member or friend can be very helpful to provide more information about your MG and advocate on your behalf. Please keep in mind that MG is a rare disease and many providers may have never seen someone with MG before, or have limited experience with MG. Your regular neurologist can always be a resource to help guide your care.

Your Notes

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Our Vision: A World Without MG

Our Mission: Create Connections, Enhance Lives, Improve Care, Cure MG

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